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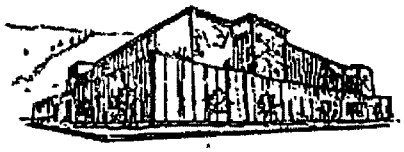
Communication and Alzheimer's disease : the perspective of the primary provider

Suzanne A. Grubaugh
The University of Montana



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Communication and Alzheimer's Disease:

The Perspective of the Primary Provider

Suzanne A. Grubaugh
Department of Communication Studies
The University of Montana
Missoula, Montana

Approved by:

Chairperson

Dean, Graduate School

4-12-01

Date

Grubaugh, Suzanne A. Communication Studies

Communication and Alzheimer's Disease: The Perspective of the Primary Provider

Director: Sally Planalp

With regard to dyadic communication between a care provider and a care receiver who has Alzheimer's disease, communication breakdown is regularly listed among the top four stressors in scales of caregiver stress and burden. The purpose for this study was to identify communication strategies and techniques that, when used by the care provider, result in effective communication. Study participants responded face-to-face, online, or by telephone to a guided interview consisting of five questions. Data gathered agrees with extant literature. Responses highlighted the importance of communication behaviors that fit into the categories of immediacy, surrogate adaptation, education and acceptance, and validation.

Acknowledgement

Humanity--the eternal, internal "essence," draws me to people with Alzheimer's disease. Communicating with a person who has AD reminds me that I am in the company of a unique and remarkable individual. I have memories to cherish, memories of conversations like the one I experienced with "Mary" (not her real name), who had AD and who lived in a long-term care facility. Mary still had lucid moments, but with ever-widening spaces between those moments.

One evening during dinner when several of us were together in the dining room of the home, Mary spoke my name. I turned toward her and raised my eyes into the warm glow of her smile. "Yes, Mary?" She continued to smile at me. "Oh, you're so beautiful!" she beamed.

"Why, thank you, Mary! You always make me feel so good! You should be around first thing in the morning, though, when I look in the mirror. I'm definitely not beautiful then."

Mary stared at me as if I had taken leave of my senses, then said in a matter-of-fact tone, "Well, don't stand there so long if you don't like what you see. Just look quick!"

And then, while I continued to smile at Mary's advice, even while Mary and I maintained eye contact, even though she remained seated in the same spot, Mary was gone, and I was left wondering if she would ever be back.

There were conversations before this one with "Mary," as well as many more with other people who have AD. What intrigues me greatly about these interactions, aside from the individuals with whom I communicate, is my recurring sense of "hey-wait-a-minute!" when the person with whom I was interacting retreats back inside her- or himself. "How," I ask myself, "do I re-open the door? How do I turn the lights back on?"

I would like to thank everyone who helped me along the way: the respondents who so graciously shared their time, their suggestions, their emotions, and their memories; the professors and mentors who prodded and poked and encouraged; the good friends who read this manuscript and offered comments and suggestions (and who endured my exhaustion-induced crankiness!); and the members of my thesis committee, Sally, Alan, and Bob, who read and re-read and provided continuing support (along with many helpful suggestions). Mostly, I want to thank "Mary"--

every "Mary" I have ever known--for allowing me to journey briefly with them into their remarkable realities.

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CHAPTER ONE

1.1 The Problem

Provision of care to aging persons, both with and without dementia, centers around maintaining the person's dignity and maximizing her or his level of independence (Bohling, 1991). A person's positive self-view can endure only when her or his social environment legitimizes and validates that self-view (Swann & Hill, 1982). In everyday reality, old age is considered the least interesting phase in a person's life. Elderly people, and in particular those elders who are also care receivers, are often asked to stay out of the way, not make waves, and not be a nuisance to those who provide their care (Fitch, n.d.).

Older people may be at a conversational disadvantage in negotiating relative power and social identities. Normal everyday communication requires a continued interchange of message delivery and reception. This interchange is endangered when one communicator is disabled (Bohling, 1991). Diminished bargaining power in conversation is especially acute for elders who are ill, dependent on others for self-care, and/or institutionalized. As a result, older adults who receive care may fail to achieve a degree of deference and control

in their social exchanges sufficient to permit them to maintain a sense of positive self-worth (Dowd, 1981).

Because of the increase in the numbers of older persons, and in the numbers of older persons who have dementia, the need for humane treatment and care is imperative (Bohling, 1991). Many people with AD are cared for in the community by spouses, relatives, and friends. The caregiver role is usually assumed by the spouse, daughter, or daughter-in-law of the person with AD (Moore, 1997). Additionally, among persons with AD living at home and receiving some type of help, 73.4 percent rely exclusively on family and friends, 14.1 percent use only paid assistance, and 12.5 percent receive help from both (Coward, Cutler, & Mullens, 1990; Stoller & Cutler, 1993).

It is important for researchers and clinicians to know how the resolution of communication breakdown [for persons with AD and their care providers] changes in response to progressive deteriorations in cognitive, language, and communicative performances. Knowing what these changes are will advance our understanding of how caregivers adapt or fail to adapt to declines in cognition, language use, and communication, and which types of strategies enhance or interfere with conversation (Orange, Van Gennep, Miller, & Johnson, 1998).

Alzheimer's disease and other dementias result in the kind of trauma that can cause a loss of self-esteem over a relatively short period of time. It is easy to assume that a person who has difficulty remembering the name of her or his grandchild, or cannot recall how to use the stove, has no sense of positive self-regard. However, such an assumption is wrong and only exacerbates the effect of dementia on self-esteem (Haden, 1997). Alzheimer's and other dementias often result in significant barriers to a person's ability to meet her or his needs. It is this inability to meet one's needs that results in lowered self-esteem.

Specific symptoms of dementia that affect a person's ability to meet basic needs include: the loss of cognitive abilities including memory, orientation, judgment, problem-solving skills, visuo-spatial skills, language skills, and psycho-motor skills; changes in emotional stability including loss of initiative, depression, moodiness, personality changes, hypochondria, and paranoia; loss of social skills including appropriate conversation and humor; and changes in behavioral capabilities including toileting, bathing, eating, dressing, and walking (Haden, 1997).

Caregivers should be aware of the threats of dementia to self-esteem, and should take active roles in mitigating

the negative effects of dementia on self-esteem (Haden, 1997). The harm that is done to a person with dementia when the care provider treats that person as someone unable to communicate is worse than the harm that is done by treating an unable person as someone who has intact communicative ability (Jansson, Norberg, Sandman, Athlin, & Asplund, 1992-1993). A care provider must recognize the emotional needs of the care receiver.

To recognize the emotional needs of the care recipient, and particularly of the care recipient who has dementia, means we must not discount that person's communication efforts based solely on explanations of her or his lack of insight, memory, or meaningful utterances. We should, however, be cognizant of the dissonance that exists between the actual abilities of the person with AD and that person's own perception of those abilities. Lack of awareness of her or his own diminished insight and declining communication abilities results in difficulty with interpersonal relationships for the person with AD. Existing literature suggests that lack of awareness on the part of the person with AD also has a negative effect on caregivers and on their relationships with care receivers. Especially with regard to marital relationships in which one spouse has AD, such unawareness causes a discrepancy in

the couple's perceptions which, in turn, creates an absence of shared experience (Cotrell, 1997).

In a study of people with AD in natural settings, participants demonstrated that the person with AD retains the ability to use politeness strategies even during the moderate and severe stages of the disease. These study participants adjusted their language according to the situation, their intention, and the hearer (Mace & Rabins, 1981; Temple, Sabat, & Kroger, 1999). Another study demonstrated that people with AD retain old social skills and the ability to make customary social remarks longer than they retain insight or judgment (Mace & Rabins, 1981). In other words, while it may sometimes seem to both the care provider and the care receiver with AD that the receiver is a fully cognizant participant in the communicative interaction at hand, that may not be the actuality.

Still, one should not assume that lack of awareness on the part of the person with AD protects her or him from the emotional effects of deterioration (Cotrell, 1997). Although absence of insight may conceivably shelter the person with AD from awareness of declining function, many people with AD are very aware of the feelings and impressions others have of them. Concurrently, they lack

the ability of self-evaluation regarding their own functioning and are therefore unable to understand or exert control over others' impressions (Cotrell, 1997).

Particularly in late life, friendships enable one to enjoy new challenges and to cope with changes, while offering continuity over the years. This continuity appears to benefit the self-esteem and the vitality of the person with AD. Diminished ability to initiate or respond to communication creates a demoralizing situation for the person with AD. The person becomes increasingly isolated and alienated from friends.

Socialization with peers is very important to persons with dementia (Haden, 1997). One study reveals that people with AD relate they have difficulty in responding to insensitive remarks made by other people (Moore, 1997). Many individuals with AD report knowing that their family and friends are talking about them behind their backs. A survey of persons with aphasia revealed that about 70% of those surveyed felt people avoid contact with them because of difficulty with communication (National Aphasia Association, 1988). Additionally, the stigma of Alzheimer's and other dementia is "so pervasive in our society that even family and friends have a tendency to withdraw" from the person with AD (Haden, 1997).

We must continue to try to learn, through dedicated study, about the natural communication process between the care provider and the care receiver with dementia in order to foster, for both people, an environment conducive to maintaining positive self-regard. As Alzheimer's advocates, we need to establish strategies and techniques that members of multidisciplinary teams and all caregivers can use to preserve and sustain such an environment (Whitcomb, 1993).

It is important for us to attend to identification of communication skills considered effective with people who have dementia (Bohling, 1991). The ability to manipulate language to satisfy needs and desires and to express thoughts, values, and observations directly influences the quality of life for any individual (National Institute on Deafness and Other Communication Disorders, 1999). Caregivers have reported high levels of frustration and anxiety because of the frequent problems in communication (Orange et al., 1998). Communication breakdown is regularly listed among the top four stressors in measures of stress and burden of AD caregivers (Ripich, 1999).

It is important for the care provider to recognize her or his own communication style (Americo, 1998). Caregivers may be able to overcome progressive declines in

communication performance on the part of the person with dementia if they adjust their language, speech, and nonverbal components of their communication, the environments in which communication takes place, and their attitudes, perceptions, and expectations of performance (Orange et al., 1998; Haden, 1997). People with dementia have demonstrated improved emotional, cognitive, and behavioral functioning when family caregivers were trained in conversation, memory-provoking exercises, and problem-solving techniques (Bohling, 1991). Techniques, including those related to communication, that bring comfort, meaning, and joy can easily be learned by motivated caregivers (Whitcomb, 1993). Opportunities to acquire education and information, as well as identification of the specific areas of awareness and unawareness for the person with AD, could provide objective understanding for caregivers and guide them toward more effective communication and interaction (Cotrell, 1997; Sabat, 1997).

The role of psychosocial factors may be critical to a complete understanding of the experience by the person with AD of her or his own disease. It is important to remember that people who have AD also continue to cope with and adapt to a serious illness (Cotrell, 1997). AD affects a person's ability to think, communicate, and perform the

basic activities of daily living. Disorders of language can adversely affect the ability of the person with AD and the caregiver in the process of communication, and thus diminish the quality of life for all concerned (Sabat & Cagigas, 1997).

Like everyone, the person with AD experiences feelings of joy, sadness, fear, anger, and jealousy. The caregiver needs to recognize and respond to these feelings. Persons with AD need to feel valued, worthwhile, and positive about life (Alzheimer's Association, Greater Austin Chapter, 1999). Since quality of life consists of both affective and cognitive components, individuals with significant cognitive deficits, such as persons with dementia, experience decreased levels of well-being. Because such individuals have reduced ability to interpret and adapt to a given situation, and because they are unable to verbalize their psychological discomfort, they often display their frustrations as agitation and other problem behaviors (Hall, Gerdner, Stauffacher, & Buckwalter, 1995; Volicer & Bloom-Charette, 1999).

A person's feelings affect her or his behavior. Limitations in a person's ability to communicate effectively cause frustration that can lead to catastrophic reactions. As a person with dementia becomes upset, her or

his ability to think or reason temporarily declines even more (Mace & Rabins, 1981). Problems of behavior in the relationship between the person with AD and the caregiver are similar whether the provider is a family member, a professional, or a para professional. Men and women who are caring for a spouse with dementia tend to share a common experience. They spend similar amounts of time performing similar tasks, and report comparable levels of emotional strain (Spousal Caregivers Overcome Gender-Role Stereotypes, 1996). Care providers for people with AD experience changes in their roles and responsibilities within the family. They are at risk for social isolation and financial depletion (Bayles & Kaszniak, 1987). Caregivers the world over face the same problems (Mace & Rabins, 1981). If, by attending to the communication needs of a person with dementia, we can help that person to feel more secure and comfortable, existing behavior problems may decline (Mace & Rabins, 1981).

Experience tells me communication between a care provider and a care recipient with AD is frustrating for both people. What constitutes a communication barrier for one person may not be a barrier for another. Communication wants and needs vary among individuals or for the same individual in differing environments (Rao, 1993). Often,

the care provider ceases communication attempts because of what she or he perceives as the care receiver's lack of response. The receiver senses the provider's frustration, simultaneously experiences her or his own overwhelming communication barriers, and also stops trying to interact. For both the provider and the receiver, those aborted communication attempts result in increasing emotional and social isolation.

Based upon her or his inability to communicate with words, a person in the middle to later stages of AD may be characterized by the care provider in ways that emphasize her or his confused nature. Misperceptions on the part of the care provider are likely to have a negative effect on the ability of the person with AD to interact, thus creating distress for all parties (Cotrell, 1997). The resulting negative behavior on the part of the care provider (i.e., the care provider may view the person with AD in a negative light and consequently treat that person as someone unable to communicate) may lead to even less effective communication (Sabat & Cagigas, 1997). Sabat notes, "It is clear care should be taken not to characterize [persons who have AD] as being unable to communicate, as this can lead to negative reactions on the part of the afflicted person" (1997, p. 344). The person

with dementia can be easily positioned as being outside of the established and commonly used language format--not because she or he cannot communicate, but because she or he has dementia and therefore may be using a different means of communication (Harre & Gillet, 1994).

Affectionate communication is critical for the development and maintenance of personal relationships (Floyd, 1997). As AD progresses, communication can become increasingly challenging. Sensitive, ongoing communication is important, no matter how difficult it may become or how confused the person with dementia may appear. Although the person with AD may not respond, she or he still requires and benefits from continued communication (Steps to Enhancing Communication: Interacting with Persons with Alzheimer's Disease, 1997). Because it is very difficult to understand the facial expressions of a person in the advanced stages of AD, there is a risk the care provider will stop trying to understand the care receiver's communication, will take over decision-making, and will not attend to the receiver's nonverbal cues at all (Jansson et al., 1992-1993). It seems reasonable to assume that in the daily care of persons in the most advanced stages of AD, caregivers perceive their patients in an intuitive way (Jansson et al., 1992-1993). In one case study, for

example, it became possible for the care providers to view the person in the terminal stage of AD as capable of having experiences and of communicating them to the caregivers (Jansson et al., 1992-1993).

If a care provider is able to learn to listen for the deeper meaning of what is being communicated by the person with dementia (Bohling, 1991), that provider will become more responsive to the needs of the care receiver. As the care provider perceives an increase in appropriate responsiveness by the care receiver, the provider becomes more willing to engage in communication with the recipient (Lantz, Buchalter, & McBee, 1997). Such responsiveness to the person with dementia, according to Bohling, constitutes a perspective shift on the part of the care provider that impacts that provider's attitude toward the care receiver. Attitude change and positive response to the emotional and psychosocial needs of the person with dementia will influence that person's sense of being heard, her or his sense of being a human being worth listening to and, ultimately, her or his sense of dignity and self-worth.

There appear to be many communication dyads comprising the "care provider" and the "care receiver who has Alzheimer's disease" wherein ongoing, successful communication does occur. Is there a specific

communication strategy that, when used by the care provider, results in communication the provider describes as "successful?" Can that strategy be identified and described? Might that strategy then be used by care providers whose communication is less successful? This study explores these questions by asking, "How do people who communicate regularly, on either a lay or a professional basis, with a person who has Alzheimer's disease adapt their messages in order to facilitate communication?"

1.2 Alzheimer's Disease and How It Affects Communication

Memory loss, disorientation, and confusion are not part of the normal aging process. They are symptoms of dementia. Dementia represents a decline in previous capabilities; it is a widespread impairment of thinking abilities that usually worsens over time and interferes with normal activities such as working, cooking, shopping, bathing, grooming, and holding a coherent conversation (Case Western Reserve University, 1997). The most common form of dementia is Alzheimer's disease (Case Western Reserve University, 1997; Hingley, 1998).

Alzheimer's disease (AD), first described by Alois Alzheimer, M.D., in 1906, is a progressive, irreversible

neurological disorder. It is a degenerative disease that attacks the brain and results in impaired memory, thinking, and behavior. It impairs cognitive functions of the brain such as language skills, memory, ability to care for oneself, and sense of time and space. AD can also cause personality change and emotional instability. Many of what we consider to be natural instincts are altered by the process of AD (Case Western Reserve University, 1997).

Alzheimer's disease affects approximately five million American adults (Hingley, 1998; Tebb, 1995). By mid-21st century, that number may reach 14 million (Nadler-Moodie & Wilson, 1998). It is estimated that one in ten families has one member with AD (Nadler-Moodie & Wilson, 1998). There is evidence to suggest genetic factors may play a part in some forms of AD (Case Western Reserve University, 1997). Alzheimer's disease is the fourth leading cause of death in adults (Nadler-Moodie & Wilson, 1998).

Of the more than 33 million adults in this country age 65 and over, about 20 percent have a speech or language disorder that prevents them from expressing themselves or limits their ability to understand others (Mandel, Shulman, & Begany, 1997). More than eight percent of all older people, and up to 11 percent of those over age 65, have dementia (AD is the most common) characterized by declines

in memory, cognition, and intellect that often impair self-expression but do not impair the ability to speak (Mandel, Shulman, & Begany, 1997). Alzheimer's disease afflicts one in ten people over age 65 and nearly half of all people age 85 and over. People with AD live an average of eight years after onset of the disease, though some individuals live up to 20 years after the onset of symptoms (Hingley, 1998).

Alzheimer's disease affects perhaps twice as many women as men (Obler & Albert, 1980), but the strongest risk factor for this disease is advancing age. (To explain: the development of AD is *related* to age, but it is not a *function/result* of age. One does not develop AD simply because she or he is older. However, the older one becomes, the more statistically likely one is to develop AD. For example, the prevalence of dementia is approximately three percent for persons ages 65 to 74; it is 18.7 percent for persons ages 75 to 85; it is nearly 50 percent for persons over age 85 (Case Western Reserve University, 1997).

Of those older adults with dementia of the Alzheimer's type (DAT), the percentage who experience language and communication problems is estimated to range from 90 to 100 percent (Orange et al., 1998). One study indicates language disturbances are an "almost universal finding"

among many people with AD (Appell, Kersatz, and Fisman, 1982).

Persons who have dementia share certain similar characteristics of language use, including a lack of initiative in speech, perseveration, naming and word-finding difficulties, and lack of appropriateness in response. The communication difficulties experienced by a person with dementia are the result of deficits in thinking, generating, and ordering ideas (Bohling, 1991). Different forms of dementia manifest differently (Obler & Albert, 1980), and the rate of functional decline for people with dementia accelerates with the severity of the disease (Mitnitski, Graham, Mogilner, & Rockwood, 1999).

Warning signs of AD include memory loss affecting job skills, difficulty performing familiar tasks, language problems, time and/or space disorientation, poor or decreased judgment, problems with abstract thinking, misplacing things or putting them in inappropriate places, mood, personality, or behavior changes, and passivity and loss of initiative (Case Western Reserve University, 1997; Grant, 1998; Hingley, 1998). The person with AD may experience confusion and difficulty finding words, finishing thoughts, or following directions. Often, people with AD have difficulty understanding what other people

tell them; they quickly forget what they previously understood; they may be unable to understand written information, even though they can still read the letters or words (Mace & Rabins, 1981). (One writer believes that AD is "not completely the result of organic impairment. Rather, it is a kind of collapse or paralysis in the face of an overwhelming situation" [Fitch, n.d.]).

At a basic level, AD is a change in the way a person categorizes things. There is less separation between categories as well as a loss of discrimination between items in a specific category. Concepts shift and become diluted until at a certain point, the person loses all awareness of his or her environment. Loss of environmental awareness further decreases the likelihood of successful communication, because the person with AD loses even the awareness that there are others with whom it may be possible to communicate.

Individuals with AD have an awareness deficit: they have diminished knowledge regarding their own cognitive, behavioral, sensory, or motor functioning. People with an awareness deficit are unable to recognize the difference between expectations for their performance and how they actually perform. They demonstrate an inability to acknowledge apparent and sometimes dramatic impairment in

functioning (Cotrell, 1997). Adults with AD are capable initially of reflective self-awareness about their speech and language, although such metalinguistic awareness diminishes as the disease progresses (Kemper, 1997).

Empirical studies have confirmed that awareness deficits occur frequently in people with AD. Not only are such individuals often unaware of their memory deficits, nearly one-half of those in the study sample rated themselves as having above-average memory when compared with a mean score of normal elderly on a self-rating questionnaire (Cotrell, 1997). Absence of insight is a significant problem for a person with AD. Lack of insight regarding disability prevents the use of strategies that compensate for cognitive losses (Cotrell, 1997).

For the person who has AD, meaning is often lost even in mild or early stages of the disease. Adults with probable AD experience not only working memory limitations, but also semantic impairment, as well as general cognitive deterioration (Kemper, 1997; Revonsuo, Portin, Juottonen, & Rinne, 1998). For effective communication to occur, the receiver must be able to comprehend and evaluate what was said. The way in which the care receiver with AD responds to statements made by another person will be appropriate to the message she or he received, but not necessarily

appropriate to the message intended by that sender (Mace & Rabins, 1981).

Metalinguistic judgments by adults with probable Alzheimer's reflect the breakdown of semantic information about verbs (Kemper, 1997). Narrations by persons with AD are less chronologically organized than are those offered by normally-aging older adults. The stories of people with Alzheimer's contain fewer salient events (e.g., marriage, career, children, education) and have few or no detailed descriptions of events (Usita, Hyman, & Herman, 1998).

One of the earliest manifestations of AD is an inability to acquire and retain new information and to integrate it with previously acquired knowledge (Hamdy, Turnbull, Norman, & Lancaster, 1990). Memory for events is impaired early in the course of AD. Unlike normally aging individuals, people with AD show rapid forgetting of events (Bayles & Kaszniak, 1987; Mace & Rabins, 1981). Because the receiver is less able to acquire, retain, and integrate new information than previously, the responsibility for successful communication falls progressively more to the sender.

People with AD have a temporal-spatial deficit that makes it difficult for them to retrieve information in explicit memory tasks (the person cannot retrieve the

context in which the information was acquired). By contrast, implicit memory tasks do not require retrieval of this information (the person need not know when or under what circumstances the information was acquired). Therefore, the person with AD will more effectively accomplish tasks that require implicit memory than those tasks requiring explicit memory (Cotrell, 1997). For example, after receiving feedback about memory deficits, the person with AD may ask for reminders and avoid memory-intensive tasks, yet continue to deny both the deficit and the memory of the feedback experience (Cotrell, 1997).

Bayles & Kaszniak (1987) note people with dementia have particular impairment of the capacity to form ideas (semantic memory), and specifically, with a subset of semantic memory called "episodic memory" (the memory of events the individual experiences throughout life). Recent neurobiological results suggest events are stored temporarily in one or other related areas of the brain immediately as they happen, and over days and weeks, transferred to other locations for permanent storage (Episodic Memory, 1999). Episodic memory deficits affect communication because the person with AD may be able immediately to repeat what she or he hears but may be unable to store what was said (Mace & Rabins, 1981). The

person with AD can talk, but the message lacks appropriate coordinated input that normally comes from semantic and episodic memory (Bohling, 1991).

Semantically-associated misnaming appears to be the most common communication barrier (Bayles & Kaszniak, 1987). Such misnaming appears to be the result of misperception on the part of the person with AD (Bayles & Kaszniak, 1987). While word memory (lexical representation) remains intact for most people with dementia (Bayles & Kaszniak, 1987), persons with AD have confrontation naming deficits (they are unable, when presented with an object, a picture, or a drawing of an object, to provide its name) (Bayles & Kaszniak, 1987; Mace & Rabins, 1981; Revonsuo, et al., 1998). One study demonstrated that when persons with AD could not name an object, they typically substituted the name of an item from the same category. Conversely, and in the same study, normally-aging adults were more inclined to define a word by giving a multi-word explanation of its meaning rather than a superior synonym (a word from the same category) (Bayles & Kaszniak, 1987).

Often, a person with a brain impairment has difficulty understanding what other people say, and also quickly forgets what she or he earlier understood. The person who can comprehend what she or he is told in person may not be

able to understand what she or he is told over the telephone (Mace & Rabins, 1981).

The person who has dementia maintains considerable linguistic knowledge but her or his ability to communicate, or to use that knowledge to share information, is impaired (Bayles & Kaszniak, 1987; Kemper, 1997; Revonsuo et al., 1998). They retain the ability to produce the sounds of their language and to order them appropriately until they are in the advanced stages of the disease; people with dementia can apply this phonologic knowledge, yet be unable to communicate meaningfully (Bayles & Kaszniak, 1987; Mace & Rabins, 1981). Clinical experience suggests people with dementia violate conversational rules, but not purposefully (Bayles & Kaszniak, 1987; Bohling, 1991; Mace & Rabins, 1981).

Anomia (inability to find the right word) and agnosia (inability to recognize and name objects) are characteristic features of AD (Hamdy et al., 1990). In the early stages, the person is usually aware of these deficits and may try to make up for them by using sentences to describe the object she or he cannot name (paraphrasia) (Bayles & Kaszniak, 1987; Hamdy et al., 1990). As AD progresses, the agnosia becomes more extensive and the person cannot use sensory information to recognize objects

or people (Hamdy et al., 1990). Research indicates that as such changes occur, people with AD may develop non-verbal forms of communication to compensate for their lack of verbal fluency (Sabat & Cagigas, 1997). As time goes by, the anomia becomes quite marked, and the paraphrasia becomes less related to the target word and more rambling. This is worsened by the person's inability to concentrate for any length of time or to comprehend spoken and written language (Hamdy et al., 1990).

Marked impairment in reading comprehension is the most distinguishing characteristic of persons with dementia (Bayles & Kaszniak, 1987; Revonsuo et al., 1998). The person may have trouble understanding written information even while she or he can still read the letters or words (Mace & Rabins, 1981). Aphasia prevents the person from understanding what she or he hears, from following instructions, and from communicating needs (Hamdy et al., 1990). As AD progresses, spontaneous speech deteriorates. The person tends to repeat words and questions (echolalia) without making any attempt to answer the questions (Bayles & Kaszniak, 1987; Hamdy et al., 1990). With further disease progression, the person repeats the same word (paralalia) or the first syllable of a word (logoclonia) over and over. The speech of the person in the advanced

stage of AD is unintelligible and the person eventually becomes completely mute (Hamdy et al., 1990; Mace & Rabins, 1981).

A characteristic symptom of AD is difficulty associated with memory-related communication (Larkin, 1998). There are several other problems relating to communication with a person who has AD. These include short-term memory loss, poor ability to concentrate, extremely slowed response to stimuli, possible hearing difficulties, and decreased ability to understand written and/or verbal communication (Bridges, 1999).

Communication by the person with dementia includes overuse of stereotype (overused phrases), reduced number of ideas being produced, reduced phrase length, increased number of repetitions, irrelevancies, intrusions, diminished vocabulary diversity, more frequent use of indefinite references, lack of abstract content, and mid-sentence dropping of initial appropriate semantic intentions (Bayles & Kaszniak, 1987). Alzheimer's disease poses a serious threat to ongoing, successful communicative interaction.

Progression of the disease is not the same for all people with AD, but it does tend to follow a pattern of "reverse development," with the last learned and most

complicated functions being lost first (Volicer, 1998). Although AD manifests differently in everyone, there are three identifiable stages. Each stage requires the sender to use different communication strategies. This means the sender must first educate her- or himself about the disease, the manifestations and unique communication barriers of each stage, and about the individual receiver. Then, after integrating this information, the sender must accordingly adapt her or his communication strategies in order to achieve successful communication.

The first, or earliest stage--the forgetfulness stage, can be difficult to recognize. Even in this stage, the person with AD may lose the ability to understand words or phrases (Obler & Albert, 1980). Individuals in the early stage of AD primarily exhibit subtle problems with word retrieval (anomia) and comprehension of abstract language (i.e., metaphors) (Orange, et al., 1998). The affected person almost always experiences memory loss as well as some difficulty in learning new material. In this initial stage, the person will seem more forgetful. She or he may misplace things or have trouble recalling names and places, and often will demonstrate topographical disorientation. The person may notice her or his own forgetfulness and try

to overcompensate for the memory loss by keeping detailed lists or by becoming excessively orderly (Hingley, 1998).

During the second, or confusional stage, the person's memory deteriorates further. The person who has AD begins to demonstrate deficits in short-term memory, though her or his recall of events in the distant past usually remains clear. Individuals with middle-stage Dementia of the Alzheimer's Type (DAT) use fewer nouns and verbs, have reading comprehension difficulties, and have significant problems understanding what is said in everyday communication (Orange, et al., 1998). The person may have difficulty finding the right words to express her- or himself, and may demonstrate disorganization of syntax (word arrangement in a sentence or phrase), paraphrasias (different phrasings or rephrasings), neologisms (new meanings for existing words), dysphasia (inability to find the right word), and perseveration (persistence of an idea, word, or experience) (Obler & Albert, 1980; Revonsuo, et al., 1998). She or he may find it hard to handle change and new situations, and problems with concentration and decision-making also become evident. These dysfunctions interact with memory disorders to such a degree that they impair coherence of thought or expression (Obler & Albert, 1980).

During the beginning of this stage the person may experience depression, but this typically subsides as the person's intellectual decline advances. Cognitive functions such as calculation, reasoning, and judgment show deficits, sudden and unpredictable mood changes may occur, and the person will require increasing assistance with daily living tasks (Case Western Reserve University, 1997; Obler & Albert, 1980).

The dementia stage, which is the third stage, is characterized by obvious disability when the person can no longer function independently. She or he experiences severe confusion and disorientation, possible hallucinations, paranoia, and delusions, possible violent or angry outbursts alternating with extreme docility or helplessness, wandering, incontinence, and neglect of personal hygiene (Hingley, 1998). Disturbances in sleep patterns become apparent, as do deficits in speech and motor abilities. The person with AD sometimes experiences seizures in the latter part of this stage, and motor system degeneration ultimately occurs. Also in the latter part of this phase of AD, cognitive and emotional functions are severely deteriorated, and the person remains in bed, is unable to speak, has limited receptive language abilities, and is incontinent (Hamdy, et al., 1990). She or he

usually succumbs to an infection of the lungs or urinary tract or a decubitus ulcer ("bedsore").

In addition to there being three identifiable stages of AD, there are three groups of people with AD: those for whom memory problems are most prominent (striking memory impairment, defective processing of abstractions, set shifting, and naming deficits); those for whom aphasia is most prominent (dramatic and progressive language impairment and associated, though less striking, memory and abstraction problems); and those for whom visuospatial impairment is most prominent (dramatic visuospatial deficits early in the disease course and some other, less striking, cognitive problems [Bayles & Kaszniak, 1987]).

For successful communication to occur, then, the care provider (a.k.a. "sender") must utilize a variety of communication strategies, depending upon the receiver's "group" membership. The sender's choice of appropriate communication strategy and the resulting successful communication depends upon the extent of that sender's knowledge about the disease, the receiver's primary communication barrier(s), and the sender's acceptance of greater responsibility for adaptation.

Though individuals who fall into each of the three groups have in common feelings of frustration and even

anger because of the unique challenges they encounter, their communication skills and abilities will differ. Communication methods one might use when interacting with a person in any one subgroup may be inappropriate for use in dyadic communication with a person who falls within a different subgroup. For example, when one communicates with a person for whom memory problems are the primary barrier, that communication may consist of frequent verbal or written reminders and considerable repetition. However, if the sender attempts the same communication strategy with a person for whom aphasia is the primary difficulty, or with a person whose primary challenge is a visuospatial deficit, both the sender and the receiver will likely experience only added frustration and anger. Reminders and repetition are of little use in communicating with a person who can neither use nor understand spoken or written communication, or with someone who is confused about how to reach the opposite end of the hallway.

1.3 Achieving Successful Communication

There is a lovely, flowing interconnection that binds all things; this includes the network that encompasses people with AD, their families, and their friends. The isolation and alienation of AD eats away at this connecting

network. Lack of effective, successful communication between persons with AD and those without AD enlarges the feelings of frustration and "differentness," and it increasingly becomes easier for the person who does not have Alzheimer's to refrain from attempts to communicate with the person who does have AD. Current understandings of AD and related problems must include a sensitivity to the emotions and the grief experienced by people living the losses of Alzheimer's (Moore, 1997). Improvement of dyadic communication between care receivers with AD and care providers will help to alleviate the frustration experienced by both communication partners.

According to Haden (1997), care providers must become "surrogate adapters." Most of the responsibility for communication will lie with the caregiver (Americo, 1998). In any communication, each participant continually adapts to the other(s). When a caregiver communicates with a person whose communication skills and abilities are compromised because of dementia, the requirement for awareness of the need to adapt, as well as for the subsequent adaptation to happen in order for successful communication to occur, falls more heavily on the care provider. The provider must anticipate and accommodate the communication needs of the person with AD for whom she or

he provides care (Americo, 1998; Bohling, 1991; Bridges, 1999).

Mandel, et al. (1997) suggest the sender should not expect to communicate with the person who has AD the same way they would communicate with a non-impaired person. Rather, the sender should "be prepared for a new approach in which [she or he] acts as a communication partner whose job it is to facilitate the [receiver's] self-expression and comprehension" (p. 57). Although persons with AD may have difficulties using language, they often retain the ability to use facial expression, to make gestures, or to point to an object. Their daily behaviors are also a form of communication, expressing their emotional states. For example, analysis of data collected during a study of agitated behaviors in nine nursing home patients suggests that agitation often serves as a form of communication (Ragneskog, Gerdner, Josefsson, & Kihlgren, 1998). The caregiver must become a "creative listener," looking at both the verbal and the nonverbal communication of the receiver (Alzheimer's Disease: Communication Strategies, 1994).

Communicators may employ strategies for communication management when they are attempting to adapt positively toward the situation and the receiver, when they desire a

higher level of clarity, when they attempt to meet the receiver's communication needs, and when their overall perceptions about the situation and the receiver are positive (Chen, 1997). Understandably, when the care receiver's dysfunction is cognitively, emotionally, socially, and behaviorally based as a result of dementia, the use of such adaptive strategies and techniques by the care provider becomes more difficult.

Sensitive listening is an important part of the communication process, and perspective-taking (a sensitive listening skill) can improve the sender's ability to understand messages verbalized by the receiver with AD (Barrett-Lenard, 1982; Bohling, 1991; Hauser, 1984; Preiss & Wheeless, 1989; Rhodes, 1987; Samter, Burleson, & Badsen-Murphy, 1989; Touzinsky, 1998). A 1991 meta-analysis of literature about sensitive listening and AD offers the following caveats for senders who want to engage in successful communication with a receiver who has AD: incorrect word choices by the receiver probably offer a categorical clue to the correct meaning or word choice; missing words may be parts of commonly-heard semantic phrases; and the receiver has short-term memory difficulties, so chosen words and phrases may be drawn from long-term memory experiences (Bohling, 1991). The sender

who practices perspective-taking should identify and focus on the communication processes still in place for the receiver with AD, rather than attending only to that receiver's speech and language deficits. This shift in perspective, according to Bohling , ". . . can positively impact a caregiver's attitude in communication responses" (1991, p. 262).

A myriad of concrete suggestions have been proposed as being facilitative of effective communication between a care provider and a care receiver who has AD. A list of suggestions for verbal communication includes the following items: never speak about the receiver as if that person were not there; avoid pronouns; avoid expressions that could be taken too literally; be specific about things, places, and activities; use words that are familiar to the receiver, including words in the person's native language; talk about things the receiver remembers; emphasize or repeat key words; repeat comments or unanswered questions using the exact same words; use repetition even in paraphrased form; speak normally and greet the receiver politely; identify yourself; address the receiver by name; avoid open-ended questions (or conversely, use open-ended questions to encourage the receiver to think, unless to do so appears to cause frustration for the receiver); turn

questions into answers; never "quiz" the receiver; break instructions into clear, simple language; use one-step commands; ask only one question at a time; limit conversation to one topic; do not use patronizing talk; speak to the receiver in a respectful, adult-like manner; offer a guess or supply a word the receiver seems to be unable to recall; avoid criticizing or correcting; try never to contradict or argue with the receiver; speak slowly, calmly, and deliberately; encourage the receiver to continue to explain her or his thoughts; use reflection; and summarize important points (citations at end of this section).

Persons with AD may be especially attuned to nonverbal cues (Bohling, 1991). People with AD compensate for their language-based difficulties by becoming very sensitive and adept to nonverbal communication, including gestures, tone of voice, and touch. Further, they become more intuitive, able to read a person's emotional status and discern easily if a person is uncomfortable around them (Alzheimer's Disease: Communication Strategies, 1994)). Suggestions for effective nonverbal communication by the care provider include the following: demonstrate those nonverbal behaviors that indicate greater immediacy (small orientation angle, touch, positive facial expression);

smile; offer comfort and reassurance; demonstrate concern; be patient and supportive; remain pleasant, calm, and relaxed; convey an easygoing, non-demanding manner; take the hand of the receiver; put an arm around the receiver's waist or in some other way express physical affection; look directly at the receiver/maintain direct eye contact; treat the receiver with dignity and respect; remain aware of your vocal tone; lower your voice tone/pitch; respect the personal space of the receiver and observe her or his reaction as you move closer; if the receiver paces, walk with that person while talking; be aware of your stance; point to, touch, or demonstrate the use of objects; supplement words with gestures or visual cues; hand the person objects; model behavior; be sure the receiver hears you; allow enough time for the receiver to respond; encourage nonverbal communication; focus on feelings rather than facts; allow the receiver to become familiar with you; establish as deep a connection as possible with the receiver; and match nonverbals to your speech (citations at the end of this section).

Ideas proposed for facilitating attitudinal changes within the sender include: remember the apparent communication breakdown is not the result of the receiver being stubborn, egocentric, or noncompliant; avoid assuming

complex reasons for the receiver's behavior; listen for meaning in what is being said; look for meaning in the various forms of communication; try to match your response to what the receiver actually communicates rather than to what you think the receiver communicates; be aware of your possible gender bias--try not to attribute a communication style to the receiver based on her or his gender; and if the communication is not working, try again later.

Suggestions for written communication are to write things down and to ascertain whether the receiver understands written communication before attempting to use that form (citations at the end of this section).

Results suggest social context may play a positive role in improving the ability of the person with AD to communicate in meaningful and effective ways (Temple, et al., 1999). To encourage successful and effective communication, the receiver must consider the environment in which that communication occurs. Suggestions for providing the appropriate environment include: eliminate environmental distractions; reduce noise, eliminate glare, institute quiet times, and remove objects such as mirrors or television; provide a calm, structured environment that revolves around a routine and offers familiarity, repetition, predictability, and minimal sensory stimuli

(citations for lists of verbal, nonverbal, attitudinal, written, and environmental suggestions:

Alzheimer's Association, 1997; Alzheimer's Disease Communication Strategies, 1994; American Speech-Language-Hearing Association, 1998; Americo, 1998; Bolinger, 1994; Bourgeois, 1990; Bridges, 1998; Case Western Reserve University, 1994; Communicating with Impaired Elderly Persons, 1998; Cotrell, 1997; Craig & Tracy (Eds.), 1983; Goodwin, 1995; Grant, 1998; Hingley, 1998; Illinois Council on Long Term Care, 1998; Jansson, et al., 1992-1993; Larkin, 1998; Mace & Rabins, 1981; Mandel, Shulman, & Begany, 1997; Mayo Foundation, 1999; Moore, 1997; Small, Kemper, & Lyons, 1997; Steinzor, 1950; Steps to Enhancing Communication: Interacting with Persons with Alzheimer's Disease, 1997; Tappen, Williams-Burgess, Edelstein, Touhy, & Fishman, 1997; Touzinsky, 1998; Whitcomb, 1993).

In addition to the individual suggestions related earlier in this section, several authors offer various concepts, each one of which consists of a constellation of communication tactics. Victoria Fitch, for instance, stresses the importance of "slowing," which she describes as "just being present in an ordinary way" (n.d., p. 103). With respect to interaction with elders in general, Fitch asserts we must "make the effort to slow to the other

person's pace, to calm our restlessness" (p. 103). When we can slow down our own pace, the elders can relax, according to Fitch, and "we can share with them the art of appreciating the moment at hand" (p. 103).

Robotham (1998) advises the care provider to encourage elders and especially persons with dementia to "talk about the past instead of the alien present." An expansion of this idea is Touzinsky's (1998) discussion of validation therapy, a therapeutic intervention developed in the 1960s by Naomi Feil. Validation therapy (VT) is "a style of communication that focuses on allowing disoriented persons to vocalize their feelings and that calls for behaviors and words to be treated as expressions of meaning and purpose" (p. 97). VT techniques include reminiscing, maintaining eye contact, mirroring a person's emotions, and appropriate touching (pp. 99-100). According to the six principles of Validation Therapy, the validating caregiver

- never argues with or confronts the person with dementia;
- does not try to give the person with dementia insight into her or his behavior;
- does not try to orient the person with dementia to time or place if the person with dementia does not want to be so oriented;

- does not use positive or negative reinforcement to affect the person's behavior;
- does not use individual or group therapies that require precise rules or orientation to present time;
- is not an authoritative teacher, but a nurturing facilitator (p. 98).

A few authors mention the importance of education for the caregiver about both AD and the individual care receiver. Importantly, in a recent study that partially parallels the current one (Beach & Kramer, 1999), the authors state, "Care providers repeatedly noted the absolute necessity of becoming familiar with each individual's history in order to establish a trusting relationship in which care receivers would be more likely to 'comply' to verbal directions" (p. 12).

Additionally, Jansson et al. (1992-1993) encourage the care provider to talk to relatives of the care receiver in order to learn more about that person's life history, and Mandel, Shulman, & Begany (1997) advise the care provider to have a spouse or someone else close to [the person with AD] in the room with the provider. "These people are usually the most familiar with the communication patterns

of the person who has AD," they note, "and can be of great help in making the communication process go smoothly" (p. 57).

Even with the abundance of suggestions for facilitating successful communication between a care provider and a care receiver who has AD, care providers continue to report high levels of stress and anxiety caused by frequent problems with communication (Orange et al., 1998), and measures of stress and burden of AD caregivers regularly list communication breakdown among the top four stressors (Beach & Kramer, 1999; Ripich, 1999). One wonders if there is a "piece" undetected by previous studies. Might it be possible that research to date, no matter how diligent and thorough, has been unable to bring to light some critical factor?

Findings in the review of literature for the current study support Beach and Kramer's (1999) contention that literature to date has "failed to provide a rationale or a justification to suggest that the common communication techniques taught to care providers [are] comprehensive or that [they] sufficiently [prepare] them effectively to provide care for the older adult with dementia" (p. 9). Extant reports of caregiver stress and anxiety caused by difficulty communicating with the care receiver who has AD

indicate diminished quality of life for both the care provider and the care receiver. Until we are able to report, qualitatively and quantitatively, a significant decrease in caregiver stress due to communication breakdown, study must continue.

CHAPTER TWO

Interviews were conducted over a period of eighteen months. Thirteen (13) interviews were accomplished face-to-face (FTF), three were online (OL), and one was by telephone. All FTF interviews and the single telephone interview were tape-recorded in their entirety. Interviews were structured and consisted of five questions, each one designed to elicit specific information (*2.2 Data Gathering*). Each respondent read her or his typed transcript and each respondent had the opportunity to edit that transcript prior to its insertion in this document.

I settled upon three different methods for data collection, but used the same instrument for all three methods (*Appendix Four: Interview Guide*). The methods I chose are the tape-recorded face-to-face (FTF) interview (# FTF = 13), the online (OL) response to the interview questions (# OL = 3), and the tape-recorded telephone (TEL) interview (# TEL = 1). Using the three different methods, I sought data indicating the care providers' gained expertise through a process of commonsense practical reasoning, whether or not that care provider understood and had applied known theory.

Managed with appropriate sensitivity, the face-to-face (FTF) interview becomes a "safe space" for the respondent,

a place where that person can share feelings as well as facts. Disclosure by the respondent of both the facts and the feelings around them helps the interviewer to gain a deeper and more complete understanding of the response. Also, the FTF setting allows the interviewer maximum freedom to observe the respondent's nonverbals and to probe for clarification.

My awareness of the importance of the respondent's feeling of "safety" as it relates to her or his ability to share led me to search for another "safe" interview method. As a part of that search, I drew upon my personal experience of having shared, via e-mail, thoughts and feelings that I had been reluctant to express in a FTF setting. Because of two factors—relative anonymity of the communicator and the communicator's control of the environment from where she or he initiates or responds to online communication, the e-mail (or "online") experience also facilitates a feeling of "safety."

The third method, the telephone interview (TEL), came about because that respondent could not meet with me for a FTF interview and did not have access to a computer to complete the OL interview. When I considered the possible benefits of the TEL method, however, several points came to mind:

- Though there was no opportunity with the TEL method for observation of the respondent's nonverbals, there was opportunity to listen for voice tone, speech rate, and pitch. Those three variables lent a color to the response that was absent from the OL forum;
- Though there were fewer cues during the TEL interview than during the FTF interview that might lead me to probe for clarification, there were a greater number of opportunities to do so than existed in the OL interview response;

Because the respondent could hear my voice, I was able to impart to him a calmness that may have helped to create a "safe space" within our interview experience.

2.1 Participants

The sample consisted of those professional and lay caregivers that either currently provide, or have within the past year provided care for one or more persons with AD. All participants met Luckmann's (1978) criteria of having had the experience [of communicating with a person who has AD] and of being able to articulate that experience. (For additional criteria, see *Appendix One: Criteria for Selection of Respondents [Lay Care Providers]*

and *Appendix Two: Criteria for Selection of Respondents [Professional Care Providers]*).

Though the total number of participants was small, six factors helped to encourage a degree of variation in response. These six factors are:

1) Participants came from geographically- and culturally-diverse areas: One respondent resides in Baltimore, Maryland, a densely-populated city of approximately 645,593 inhabitants (Census, 1998); two respondents are from Missoula, Montana, whose population is estimated to be 52,239 (Census, 1998); one respondent lives in Hudson, Wyoming, a rural town with a population (according to the City Limits sign beside the highway) of 231; two respondents are from Louisville, Colorado, with an approximate population of 17,871 (Census, 1998); seven respondents live in Boulder, Colorado, whose population is estimated to be 90,543 (Census, 1998); and four respondents reside in Los Angeles, California, where the population is approximately 3,597,556 (Census, 1998).

2) The proportion of female:male respondents was representative of the proportion of female:male care providers in the sample frame: Fifteen respondents were female, two were male. This proportion of female:male respondents (15:2) mirrors the estimated proportion of

female:male care providers (87%:13%) in the sample frame (Coward et al.,; Moore, 1997; Stoller & Cutler, 1993).

3) The age breakdown of respondents was representative of the age breakdown of care providers in the sample frame: The greatest number of respondents from a single age category (six) were between the ages of 56-70 years; the second-greatest number of respondents from one category (five) were those respondents ages 46-55 years. There were two respondents each in the age categories "36-45" and "over 70," and one respondent each in the age categories "26-35" and "under 25." These numbers also reflected the estimated total numbers of care providers in the corresponding age categories within the sample frame (Coward et al.,; Moore, 1997; Stoller & Cutler, 1993).

4) The number of lay (non-professional) care providers who participated was only slightly greater than the number of professional care providers: The number of lay care providers who participated was only slightly greater (n=10) than the number of professional care providers (n=7). This balance between two perspectives opened the field for possible diversity of communication methods, styles, and tactics. Common sense would maintain that the communication tactics used by professional care providers demonstrate a more homogeneous approach, since it is

probable those providers have similar theoretical and practical knowledge in the same field. Differences among lay care providers should be greater with regard to theoretical and practical knowledge than the differences among professional care providers who work in the same field.

5) Within the sample, respondents were accessed via both convenience and snowball sampling: For example, in order to gather a response from the participant who lives in Baltimore, Maryland, I followed up on an online conversation we began in a chat room.

While I was in Missoula, Montana, I worked part time as a respite care provider for families of people who have AD. I approached two of the family care providers for whom I provided respite services, explained my study, and requested their help.

The respondent from Hudson, Wyoming, is someone whose name was given to me by my relative who also lives in that town.

With regard to respondents in Louisville, Colorado, the first respondent was a neighbor who lived two houses away from me. After our interview, she referred me to another care provider who also agreed to respond to an interview.

In Boulder, Colorado, I contacted the Colorado Alzheimer's Association. I interviewed one care provider who was referred to me by the Director; that person also helped me to contact another care provider whom I later interviewed.

Next, I contacted the Chair of the Department of Gerontology at Naropa Institute in Boulder, who offered me two names of potential respondents, along with contact information and permission to mention his name. Each of these respondents offered the name of another person whom I also interviewed. Additionally, one of those participants referred me to a third person and that referral also led to an interview.

To locate participants in Los Angeles, I first spoke with a co-worker who provided care for a parent with AD. During the course of our interview, the co-worker offered the name of another care provider and my telephone call to him resulted in an interview, as well.

Because my employment brings me into contact with mental health provider agencies in Los Angeles and surrounding areas, I had the opportunity to approach the Director of the Human Subjects Review Committee in a large agency; that person then provided me with appropriate forms to complete in order to submit my request for interview

respondents. I later met with two care providers referred to me by that agency.

It should also be noted here that even though the methods of convenience sampling and snowball sampling were effective ones for gathering data in the current study, there were instances where attempts to use those two methods were not successful, and I had to redirect my effort to locate respondents. For example, the requirements placed on one potential respondent by her caregiving responsibilities created scheduling difficulties and we eventually abandoned our attempts to arrange the interview.

Also, though I did place an ad in the "Personals" section of a large newspaper, I received no response to my request. Possible reasons for lack of response are: 1) ads placed under the "Personals" heading may be culturally defined as being those advertisements placed by individuals seeking interpersonal relationships of some sort, and 2) because of that culturally-shaped definition, people who are overwhelmed by the responsibility of providing care for a person who has AD may not have time or energy to concentrate on the "Personals."

The third instance where the sampling methods selected for this study did not result in a favorable response was

when I contacted the director of a local adult day care home. My sense was that the Director was simply too busy to attend to my request. Further, I may not have communicated successfully to her the ways in which results of the study might offer future benefit for people who communicate with a person who has AD.

6) Three different methods (utilizing the same instrument) were used for data collection (further discussion of this factor is contained in the "Data Gathering" section).

2.2 Data Gathering

The Interview Guide (*Appendix Four: Interview* Guide) consisted of a set of five questions, each question designed to elicit a specific type of information. Interview questions and the purpose for each question were as follows:

"Are you able sometimes to communicate more successfully with (X_____) than you are at other times? How is the successful communication different from the less successful communication?" (TABLE 3.1). The intent behind this question was to explore the range of criteria employed by individual respondents in each person's attempt to identify "successful communication."

"Do you know what circumstances occur or what you say or do that makes your communication more successful sometimes than it is at other times?" (TABLE 3.2). The reason for this question was to explore possible elements of "successful communication," and to contrast those elements with those inherent in "less successful communication."

"Can you describe a specific interaction between yourself and (X_____) where your communication was successful? If so, why was it successful?" (TABLE 3.3). The intent of this question was to encourage respondents to personalize and to explore freely their communication with the receiver in the hope that respondents might uncover some communication behavior they failed to discern during their more general recollection.

"Are you aware of any ways in which your communication with (X_____) became different after the onset of Alzheimer's disease from the way it was before (or over the period of time during which you communicated with this person)? If so, can you describe those differences?" (TABLE 3.4). The purpose for this question was to determine if or how each respondent altered her or his communication style or tactics during communication with

the same receiver over a period of time and in response to the deteriorating communication skills of that receiver.

"Have you had the opportunity to observe other people when they communicate with a person who has Alzheimer's disease? Have you noticed some people who communicate more successfully than others? If so, can you describe the differences between the more successful communicators (SC) and the other communicators (NS)?" (TABLE 3.5). The intent of this question was to request information from respondents about the successful communication behaviors of other senders. Because of respondents' personal experiences with successful communication, it is possible their observations were more insightful than observations made by inexperienced others.

My initial contact with four of the 13 FTF respondents was in person. Each of these respondents was someone who already knew me. These individuals had already had ample opportunity to observe me professionally and we had established a bond of trust and mutual respect. We shared common interests and had already engaged in multiple conversations on the subject of communication and AD. These factors--prior knowledge of one another, existing reciprocal trust and respect, common interests, and

previous communication about the topic of this study--led to warm and richly rewarding FTF interview experiences.

The fourth FTF respondent whom I knew prior to requesting an interview had knowledge of me only as a neighbor and as someone who worked hours similar to hers. However, we had already established an easy rapport. It seemed natural for us to progress from our acquaintanceship to a warm and open exchange during our FTF interview.

In order to gain audience with an interview respondent, the interviewer must first establish credibility. It is this established credibility that aids in creating the necessary feeling of "safety" for the respondent. The interviewer establishes her or his credibility most easily if there is a pre-existing relationship with the respondent. In cases where the two people are unacquainted, the interviewer must offer as "evidence" of her or his trustworthiness someone or something the potential respondent knows and trusts and that can then serve as a sort of link, or "bridge," between the two strangers.

Prior to my initial contact with the other nine FTF respondents, we were unknown to each other. In six of those nine cases, someone whom I had already interviewed referred me to the potential respondent. Because of the

introduction offered by each previous respondent, each potential interview participant greeted my telephone contact with an openness that might not otherwise have occurred.

With the other three FTF respondents, I was able to establish initial credibility on a professional level by sharing with each potential interview participant the name and title of the referring individual, as well as the name of the organization with which that person was affiliated.

The online interview process (OL) differed from the FTF process in two significant respects: in the OL forum, I had no opportunity to observe the respondent's nonverbal cues, and I was not afforded the ongoing openings to probe for clarification. Still, the content of online responses, though generally more succinct than that of the FTF responses, mirrored FTF interview content.

I was referred to one OL respondent by someone whom I had previously interviewed FTF and who personally contacted the OL referral for me. Therefore, to establish my credibility as interviewer was an easy process.

Regarding the other two OL respondents, my first contact with each of them was online, but the online forums differed, as did the way in which I went about gaining the trust of each participant. I was directed to one

respondent by my mother who is a close friend of the respondent's mother, so this person and I had "common ground" on which to build an interview rapport.

To establish trust with the third OL respondent was more difficult. We met in an online "chat" room and she told me she worked with people who have AD; I told her about my thesis and asked her to complete an online interview. During our next chat session, she requested the name of my school, information about my thesis process, and the nature of the questions she would be asked to answer. At that point, she gave me her e-mail address and promptly completed and returned the form I e-mailed to her.

The TEL respondent was a person to whom I was referred by a Los Angeles mental health facility. He had been informed about the purpose for my study, and he knew I had met the criteria put forth by that agency's Human Subjects Review Committee. My credibility had already been established by the time I contacted this respondent.

During the process of data collection, I adhered to the procedure of *theoretical sampling* (Glaser & Straus, 1967). To use that procedure means I analyzed each transcript prior to the addition of the next transcript. I continued with subsequent interviews until information reached a "saturation point," beyond which no new

information was presented. At the "saturation point," I then conducted one additional interview as a check.

At the beginning of each primary interview, each FTF and each OL respondent read and signed the "Consent to Interview Form" (*Appendix Three: Consent to Interview*). I read the form to the TEL respondent, obtained a verbal agreement from him, then mailed the consent form to him with the request that he sign and return it to me. He complied with that request. I also asked respondents to volunteer demographic information (*Appendix Five: Respondent Demographics*) because that information, in connection with specific responses offered during interviews for this study, may help to direct future exploration.

FTF interviews lasted an average of one hour each (ranging in length from 35 minutes to 115 minutes). I tape-recorded the entire content of each interview. In every case, I was able within 48 hours of the interview to listen to the entire tape and transcribe the contents of each tape. After completing transcription, I contacted the respondent to schedule a second meeting for the purpose of allowing that person to read the typed transcript and to make corrections or deletions. Additionally, during the second meeting, each participant gave permission for me to

quote material from the transcript. When the respondent had completed the processes of reading, correcting, deleting, and granting permission to use quotes, I erased the interview tape, gave one copy of the edited transcript to the respondent, and retained a copy for my use. I also retained the disk onto which that interview was transcribed.

For OL respondents, using the same questions that comprised the *Interview Guide* I followed during FTF interviews, I created a computerized questionnaire with form fields for responses (*Appendix Six: Online Interview Form*). In addition, via e-mail I asked each participant to volunteer demographic information (*Appendix Five: Respondent Demographics*) for the same reasons I requested such data from FTF respondents. I completed a "Demographics" sheet for each participant, based upon that person's responses.

In all three cases, the "turnaround time" for OL interview responses was under 24 hours (e.g., I received the completed questionnaire and consent form from each person via e-mail within less than 24 hours from the time I e-mailed the original forms). Upon receipt of each completed questionnaire and consent form, I inserted my name, the date, and interview code in the space provided.

I did not alter the content of any data I received: I did, however, adjust spacing in order to provide for uniformity across thesis documents, but I did not change punctuation.

The TEL interview lasted 50 minutes, during which time I tape-recorded all questions and responses, including answers to demographic questions. I mailed to the TEL respondent the typed transcript as well as the *Consent to Interview* form, with a self-addressed envelope. The participant contacted me by phone when he received the transcript and the consent form to advise me he requested no changes to the transcript and to ask if he could simply retain the hard copy of the transcript I had sent to him. I granted permission for him to do so, and asked him to return the signed consent form; I received that form back from him five days after our conversation.

During the process of data analysis, I adhered to Colaizzi's (1978) framework, which puts forth the following five specific steps:

- Read each transcript in order to gain an overall sense of meaning;
- Extract all significant statements that directly relate to the phenomena being studied;
- Formulate meanings in order to capture meanings both implicit and explicit;

- Cluster statements into themes;
- Refer back to the transcripts in order to either validate themes or to identify discrepancies.

In order to ensure accuracy of the data, I added the following two steps to Colaizzi's framework:

- Contact each respondent a second time for the purpose of reviewing the typed transcript of that person's interview;
- Request permission from each respondent to use direct quotes and ask the respondent to read and grant permission for each quote individually.

With respect to my use of Colaizzi's framework, the following elaboration may be helpful. First, because I worked toward creating a strong rapport with each respondent, it was also necessary for me to work toward maintaining an objective stance with regard to the information provided by the respondent. By adhering to all seven steps in the combined framework (Colaizzi's five steps plus the two added for the purpose of this study), I maintained the necessary objective balance. My use, especially, of the two additional steps afforded the opportunity for a "reality check" with each participant regarding that person's intent.

There were several inherent aspects of the FTF interviews (both in the interview process and in the transcribing of the interview tapes) that facilitated my doing the first and the third steps in the framework. During the FTF interviews, I gathered auditory as well as visual information. The process of transcribing those tape-recorded interviews fixed the data more firmly in my mind as I listened for a second time to the participant's responses and experienced, also, the tactile sensations of typing. Because I received the data twice through visual and auditory channels, and again through a tactile channel, I retained a greater amount of information than would otherwise have remained with me. Having a more extensive fund of information eased the process of gaining an overall sense of meaning (Colaizzi's first step) and capturing both implicit and explicit meanings (Colaizzi's third step). As might be expected, the first and third steps in the framework were more difficult to complete with respect to the TEL interview, and still more so for the three OL interviews, because I received those responses via fewer channels and experienced fewer repetitions of "input."

Colaizzi's other steps--extracting significant statements, clustering statements into themes, and referring back to the transcripts--were made easier, too,

by the fact of my having a greater amount of information. Specifically with regard to OL interviews, I felt a sense of caution about the possibility of ascribing incorrect implicit meaning to a transcript when the only information before me was a document typed by someone else. In these cases, especially, the two steps I added to Colaizzi's original framework were beneficial, because they allowed me to check my interpretation of the data against the intent of the person who had offered the information.

CHAPTER THREE: Results

Respondents were able easily to understand and to answer all interview questions, and their responses gathered into common themes. Because of individual differences in wording of responses, I exercised caution during the process of response categorization in an attempt to remain true to each respondent's intended meaning. In order to allow for the manifestation of subtle but important differences in meaning, I refrained from melding of responses. For that reason, the number of response categories may be larger than might be the case if I had collapsed similar responses into one another (Beach & Kramer, 1999). (Note: the total number of responses may be greater than the total number of respondents; some participants offered more than one response to each question).

3.1 Question Number One

Are you able sometimes to communicate more successfully with (X_____) than you are at other times? How is the successful communication different from the less successful communication? (TABLE 3.1).

Approximately half of all respondents (7/17) said they knew successful communication had occurred when the

TABLE 3.1

Successful vs. Non-successful Communication	No.
Direct eye contact	7
Sender feels connection, intensity, or emotion	6
Receiver understands	5
Receiver acknowledges sender	4
Participants focus one:one	3
Depends on receiver's mood/well-being	3
Receiver smiles	2
Receiver "perks up"	1
Depends on sender's comfort level	1
More touching/tactile stimulation	1

receiver maintained eye contact. For example, one respondent stated, "Eye contact is a huge thing for Alzheimer's. If you're talking with them, eye contact becomes critical if you want them to focus."

About one-third of all respondents (6/17) identified successful communication as consisting of those instances where the sender experienced connection, intensity, or emotion. One respondent noted, "We're more focused on one another and there's a connection that doesn't always happen. But when it does, I know the communication is successful."

Slightly fewer than one-third of respondents said they knew successful communication had occurred when the receiver indicated she or he understood. "If they seem to obviously understand what you're saying rather than, you know, totally ignoring you or looking at you quizzically, then you know it's been a more successful communication."

Nearly one-quarter of respondents (4/17) identified successful communication as that exchange where the receiver acknowledged the sender. One respondent said, "When you're talking to the individual and they are comprehending what you are saying, their eyes light up, or if you're asking them to help you do something and they do, then you know that you're getting through to your person."

Three of the 17 respondents said successful communication occurred when the participants focused on each other. For example, "The successful communication is . . . a matter of both of us--myself and the person with dementia--being present with each other." Three respondents also identified successful communication as being dependent upon the receiver's mood/well-being.

Two of the 17 respondents said they knew successful communication had occurred when the receiver smiled, and one respondent shared that whether or not successful communication happened depended upon the comfort level of the sender. Finally, one respondent said that she identified successful communication as having occurred when the receiver "perked up," and one respondent identified as "successful" those communications where there was more touching or tactile stimulation.

3.2 Question Number Two

Do you know what circumstances occur or what you say or do that makes your communication more successful sometimes than it is at other times? (TABLE 3.2).

Nearly half (7/17) of all respondents said successful communication differs from less successful communication because the more successful communicator engages in direct

TABLE 3.2

What Makes Successful Communication Different?	No.
Direct eye contact	7
Eliminate environmental distractions	5
Sender uses appropriate touch	5
Sender uses receiver's name	5
One-to-one	5
Sender is "present"/focused	5
Sender monitors receiver's nonverbals	5
Sender educates self re person/disease	4
Sender probes for clarity	4
Sender uses appropriate humor	4
Depends on sender's persistence	4
Sender uses low/calm voice	4
Receiver is familiar with environment	4
Sender sits/stands close to receiver	4
Sender "slows down" demeanor	4
Depends on sender's mood/patience	3
Sender directly in front of receiver	3
Shorter/more simple statements	3
Sender uses props/objects	3
Sender rephrases/reframes	3
Depends on receiver's mood/patience	3
Concrete (versus abstract) statements	3
Sender uses redirection	2
It is always the same	1

eye contact with the receiver. Statements like, " . . . and it's looking directly into the person's eyes" and, "I look right into her eyes," are typical of responses that fall into this category.

Approximately one-third (5/17) of all respondents said successful communication happened when any of the following six circumstances existed:

- Environmental distractions were eliminated: "It really was very successful when there was no outside communication going on"; "Something very important is to have it quiet--to have the television off, to not have other people talking";
- The sender used appropriate touch: " . . . slow, caring movements, gentle touching"; "The successful communication has more touching/tactile stimulation involved"; "When I put my hand on his shoulder and on his face, it helped him to calm down and to realize we were trying to find out what had happened"; " . . . touching seems to help them focus";
- The sender used the receiver's name: "It's certainly more successful when I use a participant's name";

- The communication was one-to-one: "I think that [the communication works best] when it's just the two of us";
- Both participants were "present" or focused: "If I carry the stress of the day into the communication with a person who has dementia, the person senses that I'm not fully present. It's important for me to focus on the conversation at hand, and not go other places in my head";
- The sender monitored the receiver's nonverbals: "But I do a lot of observation, watching her."

Nearly one-quarter of all respondents (4/17) identified successful communication as consisting of those interactions during or prior to which the sender did the following things:

- Educated her-or himself about the receiver and/or the disease: "We studied the disease so we knew what to expect";
- Probed for clarity: "I feel that if I probe and talk with her a little bit I'll find out what her real feelings are";
- Used appropriate humor: "We were at the same place at the same time, laughing about the same thing, appreciating the humor in the situation.

Then, she could understand things, comprehend better . . . and you could talk to her then";

- Was persistent: "If there is a problem . . . I just walk away and . . . come back and re-approach her in a different manner";
- Used a low/calm voice: "I used a low . . . kind of like soft voice--calming voice so that person didn't feel threatened";
- Sat/stood close to the receiver: "I was right nose-to-nose with her";
- Slowed down her or his demeanor: "It's more successful . . . when I slow down not only my words but just my whole . . . demeanor."

Additionally, four of 17 respondents said successful communication occurred when the receiver was familiar with the environment: "I think a constant, persistent environment helps them."

Approximately 20 percent of respondents (3/17) said whether or not the communication was successful depended upon the mood/patience of either the receiver or the sender: "It seems like it's more a matter of how they're feeling and how they're doing on that particular day, as much as anything else"; " . . . my own level of comfort or security in dealing with a patient."

Twenty percent (3-17) of respondents emphasized that successful communication occurred when the sender

- Was directly in front of the receiver: "I try to stand in front of her";
- Used shorter/more simple statements: " . . . it was simpler communication. It wasn't too big of words or things he had forgotten how to use";
- Used props/objects: "But when she had the physical evidence in front of her and she could look at [the photographs], that's when she could recall";
- Rephrased and reframed: "I tend to ask her questions from a couple directions to make sure I'm getting the right answer";
- Used concrete (versus abstract) statements: "*So you're talking about shorter statements, concrete words versus abstract*? Right--exactly."

Two participants said communication was successful when the sender used redirection: "(X_____) was wandering in and out of rooms and she had become involved in a physical confrontation with another resident. When I saw what was happening I started walking towards the group with my arms outstretched and open and as I got close enough I called to her. Upon hearing her name called she turned and

looked, and when she saw me she stopped everything and walked straight into my arms."

Finally, one participant said the success of the communication did not depend upon any particular behavior of the sender: "A lot of times, yes, it's the same type of communication, and if the person is having a bad day, then they don't respond in the same way."

3.3 Question Number Three

Can you describe a specific interaction between yourself and (X_____) where your communication was successful? If so, why was it successful? (TABLE 3.3).

All respondents (17/17) described a specific communication episode. Of those respondents, about half 8/17) said their communication was successful because they used appropriate touch: "I always touched her when I talked to her, even when it seemed like she didn't know me"; "Appropriate touch is important."

Slightly fewer than half of all respondents (7/17) said they communicated successfully because they used direct eye contact: "Eye contact becomes critical if you want them to focus."

About one-third (6/17) of respondents indicated their communication was successful because they educated

TABLE 3.3 Discussion of Specific Communication Episode

Reason for Successful Communication	No.
Sender used appropriate touch	8
Sender used direct eye contact	7
Sender sat/stood close to receiver	6
Sender educated self re person/disease	6
Sender "present"/focused	5
Sender accepted person/disease	5
Sender observed receiver's nonverbals	5
Sender demonstrated respect	5
Receiver familiar with environment	4
Sender accepted responsibility for adaptation	4
Sender probed for clarity	4
Receiver was familiar w/sender	4
Sender and receiver on same eye-level	3
Sender modeled appropriate behavior	3
Sender used props/reminders	3
Sender used receiver's name	3
Depended on sender's mood/well-being	2
Depended on receiver's mood/well-being	2
Sender reinforced receiver behavior	2
Sender sat/stood directly in front of receiver	2
Sender expressed own vulnerability	2
Eliminated environmental distractions	1

themselves about the person and/or the disease or because they sat/stood close to the receiver: " . . . from the very beginning, when Dad was first diagnosed, we all studied . . . the disease so we knew what to expect"; "I made sure I was closer."

Almost one-third (5/17) of the respondents said communication in the specific interaction was successful because they

- Remained "present or focused: " . . . a hundred percent of everything was [focused] on them";
- Accepted the person and the disease: "If you don't accept what the disease does, it takes away people's memories and their emotions and their identity, then the disease overtakes you, and you lose your ability to just love the person";
- Observed the receiver's nonverbals: "I do a lot of observation, watching her"; and/or
- Demonstrated respect for the receiver: "I began simply by talking to her in a tone of voice which I perceived she would have become accustomed to as a teacher, with respect and dignity . . . in my voice."

About one-quarter (4/17) of respondents described the interaction as having been successful because the receiver

was familiar with the environment in which that interaction occurred ("I think a constant, persistent [sic] environment helps, and a routine"), or because the receiver was familiar with the sender ("X_____ got what she had been looking for: someone familiar".

Four of 17 respondents noted communication was successful because they

- Accepted most of the responsibility for adaptation: "[Those communicators] who are successful take into consideration that most of the responsibility to communicate is on them. [That person has] taken the time to learn a little more about Alzheimer's disease, has come to the realization that they have to change their style of communicating because they're the only ones who can control that and change that"; and/or
- Probed for clarity: "I have to do the detective work; I had to keep digging."

Three respondents communicated successfully because they

- Remained on the same eye-level with the receiver: "I just sat across from him and we kept on looking at each other";

- Modeled appropriate behavior: " . . . and my communication was as if I would have with my daughter, to show him a much simpler way";
- Used props and reminders: " . . . having her touch her food and telling her what each thing is, and explain to her it's time to eat, then most times she'll understand"; and/or
- Used the receiver's name: " . . . they have to use their name."

A small number of respondents (2/17) said communication in this instance was successful as a result of their own mood/well-being and/or the mood/well-being of the receiver: " . . . being patient and very kind with them if they don't understand me"; " . . . and it was one of her better days and she was a little more alert than she was at other times."

Two of 17 respondents said communication was successful because they

- Reinforced the receiver's appropriate communication behavior: "Praising him that he had done such a good job";
- Stood or sat directly in front of the receiver: "I was on my knees right in front of her and I was talking to her about something"; and/or

- Expressed their own vulnerability: "Now that I think about it, I think that's when I got the best response, when I was vulnerable."

Finally, one respondent said successful communication occurred because there were few environmental distractions: "But I think the most sincere thing that I got was when it was just me and that individual alone . . . no outside interference."

3.4 Question Number Four

Are you aware of any ways in which your communication with (X_____) became different after the onset of Alzheimer's disease from the way it was before (or over the period of time during which you communicated with this person? If so, can you describe those differences? (TABLE 3.4).

More than three-quarters of all respondents (13/17) said they changed their communication style or tactics because they accepted that they, as senders were responsible for adapting messages in order to make their communication successful. They understood the receiver was increasingly unable either to understand or to adapt. As senders, each became an "extended" or "surrogate" adapter for the receiver. Each sender changed her or his

TABLE 3.4

Intra-Respondent Differences	No.
Sender accepted responsibility for adaptation	13
Sender educated self re person/disease	12
Sender simplified communication	7
Sender focused more on receiver	7
Sender "slowed down" demeanor	7
Sender used more eye contact	6
Sender relied more on use of appropriate humor	6
Sender used more props	6
Sender used more touch	5
Sender modified environment	5
Sender talked more of distant past	5
Sender was more persistent/patient	5
Sender demonstrated respect	5
Sender accepted person/disease	5
Sender did not try to "bring receiver into the present"	4
Sender used receiver's name more	4
Sender sat close to receiver more often	3
Sender tried to "bring receiver into the present"	1

communication style or tactics while letting go of any expectation that the receiver would also make changes in order to facilitate successful communication: "If I didn't accept her dementia, the process of it and the changes, I wouldn't be able to communicate with her. And I know she can't communicate the same way she used to, because I don't believe she understands how to do that any more, to communicate with someone else. I have to direct the process or it doesn't happen."

Nearly the same number of respondents educated themselves about both the receiver and the dementia so they knew what to expect: "So to try to rekindle memories, you have to hunt. You have to dig. You have to look at old books, you have to look at old pictures, things they've written, things they've highlighted. I would ask families questions just so later on I could ask that person and maybe bring something back to them."

Seven of 17 respondents said that as the receiver's dementia progressed, they

- Simplified communication: "Had to break it down to very, very, very small increments";
- Focused more on the receiver: " . . . you have to kind of put your sensibilities and your reactions

kind of in the background and concentrate on what they're doing"; and/or

- Slowed down their demeanor: "I realized it was okay to slow down and communicate differently."

About one-third (6/17) of respondents said that over the course of the receiver's dementia, the senders

- Used more eye contact: "[with] someone who was at the end stage, I made sure that I . . . had eye contact";
- Relied more on use of appropriate humor: "I used to tease her"; and/or
- Used more props: "Sometimes we would give her pictures and things to look at so we could . . . kind of remind her of events that had happened."

Slightly fewer than one-third (5/17) said they adjusted their communication by

- Using more touch: "It seems now she . . . 'spaces out' . . . seems to go somewhere else for a while and I have to kind of bring her back by touch";
- Modifying the environment: "[There was] a nursing home . . . that had an Alzheimer's unit [with] toned-down colors and different stimuli . . . [communicating in] a different room where there

are no distractions . . . no other conversations going on, there's no radio or music going on";

- Talking more of the distant past: "She can talk about memories she has";
- Being more persistent/patient: " . . . when I am around her I am very patient with her";
- Demonstrating respect for the receiver: " . . . you have to certainly take into consideration that you're talking to adults . . . adjusting to their ability to understand you is critical, and that's what you have to develop over time and what changes as the disease progresses"; and/or
- Accepting the person/disease: "I expect different things from her. I expect her to be different from the way she used to be."

Four respondents of 17 indicated that as the receiver's dementia progressed, their communication was more successful when they no longer tried to bring the receiver into the present: "I try to respect the way (X_____) is now instead of trying to change him back into the way he used to be. (X_____) loved to fish . . . we look at pictures of people fly fishing and scenes of rivers. I can tell (X_____) understands those things"

An equal number of respondents (4/17) noted they used the receiver's name more frequently than was previously the case: "Every time I approached him, every time I spoke with him, I used his name"; "I think the more successful communicators use the person's name--I believe that's really important, because it helps the person to concentrate on what's happening between the two of you."

Three respondents said that over time they more frequently sat close to the receiver: "We were usually sitting together, or else she was in bed and I would be sitting in a chair by the bed, or we would be sitting together on the bed or a couch."

Finally, one respondent said she tried more often, later in the course of the receiver's disease, to bring the receiver into the present: " . . . you'd have to bring her up to the present--you know, up to speed to where she was aware that this was no longer that many years ago."

3.5 Question Number Five

Have you had the opportunity to observe other people when they communicate with a person who has Alzheimer's disease? Have you noticed some people who communicate more successfully than others? If so, can you describe the

differences between the more successful communicators (SC) and the other communicators (NS)? (TABLE 3.5).

Eleven respondents said successful communicators accepted greater responsibility for adaptation: "[Successful communicators] know that they have to govern the communication. They have to help [the receiver] because it's not a two-way thing any more"; "Certainly over the course of time, and as their disease progresses and their ability to communicate decreases, it really becomes more of a responsibility of the person working with them to make up for that deficit."

Eleven respondents said the key to successful communication was the sender's acceptance of both the receiver and the disease: "I feel that the communicators that have accepted and understand the problems with their relatives' Dx's [diagnoses] are the ones that are more able to get through to the resident."

Ten respondents noted that the successful communicators whom they had observed educated themselves about both the receiver and the disease: "I think it was important that I understood about Alzheimer's disease"; "The successful ones are the ones who take the time to learn about (X_____). They ask me questions about him and they listen when I tell them how to communicate with him."

TABLE 3.5

Inter-Communicator Differences	No.
Sender accepted responsibility for adaptation	11
Sender accepted person/disease	11
Sender educated self re person and/or disease	10
Sender "cared more"	7
Receiver was comfortable w/sender	7
Sender demonstrated respect for receiver	6
Sender was more persistent/patient	5
Depended on receiver's mood/well-being	4
Sender "slowed down" demeanor	4
Sender did not attempt to "bring receiver into present reality"	4
Sender demonstrated empathy toward receiver	4
Sender used receiver's name	3
Sender used calm/soft voice	3
Sender used direct eye contact	3
Sender used appropriate touch	3
Sender had an aptitude for this type of communication	3
Sender used props	2
Sender reduced environmental distractions	2
Sender used appropriate humor	2
Sender smiled	2
Sender was intuitive	2
Sender sat/stood directly in front of receiver	1
Sender was on same eye-level w/receiver	1
Sender observed receiver's nonverbals	1

Seven respondents of 17 said the successful communicators cared more: "The person has to show they care about [the person with AD]" and/or that receivers in those observed dyads were comfortable with the senders: "If you're comfortable it's going to carry out and you'll be comfortable around an individual and they're going to be able to respond back to you."

Approximately one-third of the respondents (6/17) indicated successful communication occurred when the sender demonstrated respect for the receiver: " . . . give that same respect to the Alzheimer's victim."

Five respondents observed that successful senders were more persistent or patient: "I think patience and just an understanding, I think are two of the most important tools of communication with someone who has Alzheimer's"; "[successful communicators] have the patience."

Slightly fewer than one-quarter of respondents 4/17) indicated that they observed successful communication was dependent upon the receiver's mood/well-being: " . . . a lot of times it does have to do with the person, themselves. How they are feeling, where they are that day, whether they're in the present or the past, and things like that."

Four respondents of 17 noted that successful senders

- Slowed down their demeanor: " . . . taking the time. That's the really important thing. Slowing down . . . it's hard to do in this fast-paced world, but it makes a difference";
- Did not attempt to bring the receiver into the present reality: " . . . it was his made-up conversation about his day, that became our conversation. It was okay to hear those stories"; and/or
- Demonstrated empathy toward the receiver: " . . . and the person has to show they care about [the person with AD], otherwise that person will just sort of drift off."

Three respondents said they had observed successful communication in those dyads where the sender

- Used the receiver's name: " . . . helping them focus using their name and getting their attention";
- Used a calm, soft voice: " . . . speaking softer works more . . . in my experience";
- Used direct eye contact: " . . . to try to maintain eye contact, to position myself in front of that person";

- Used appropriate touch: " . . . within a few feet [of the receiver] touching her on the leg"; and/or
- Had an aptitude for this type of communication: "*Are you saying that people who communicate successfully with someone who has Ad have an aptitude for it, in addition to learning the skills?* Right, exactly."

A small number of respondents (2/17) noted that senders whose communication was successful

- Used props: "[They] use props or whatever . . . you point to something";
- Reduced environmental distractions: "If there's something that you're trying to communicate to them that's very important, that has to be done . . . where there are no distractions";
- Used appropriate humor: "Make that three things: patience, understanding, and a sense of humor";
- Smiled: "I think that a friendly face, rather than a frown, a smile would help"; "I think they approach calmly and very cheerfully, with a big smile"; and/or
- Was intuitive: "It seems like they are the ones who are intuitive and (X_____) knows that."

Finally, one in 17 respondents said the successful communicator

- Sat/stood directly in front of the receiver: "If you are in front of them communicating with them and looking at them, they're a lot more likely to be able to focus on that than if you were to either side, or busy doing something else and talking to them";
- Was on the same eye-level with the receiver: "I certainly talk to staff about being on the same level. So if I'm talking to somebody who's sitting down, I need to sit down or squat down with them so that we can have direct eye contact"; and/or
- Observed the receiver's non-verbal behavior: " . . . watching body language, eyes, and being real sensitive to watching what they respond to."

3.6 Common Themes

Responses across all five categories also formed common themes (TABLE 3.6). Predominant among the themes were the following five responses, and the total number of times each response was generated:

- Sender educates self re person/disease (32);

TABLE 3.6

General Categories Common Themes	No. of Times	% of Total (405)	% of Category
Immediacy	167	41%	
Sender uses direct eye contact	30		18%
Sender uses appropriate touch	22		13%
Sender uses receiver's name	15		9%
Sender and receiver are one-on-one	15		9%
Sender "slows down" demeanor	15		9%
Sender uses appropriate humor	12		7%
Receiver is comfortable w/sender	11		7%
Sender is "present"/focused	10		6%
Sender is intuitive or feels connection, intensity, emotion	8		5%
Sender "cares more"	7		4%
Sender uses calm/low/soft voice	7		4%
Sender sits/stands directly in front of receiver	5		3%
Sender and receiver are on same eye-level	4		2%
Sender smiles	2		1%
Receiver smiles	2		1%
Sender expresses own vulnerability	2		1%
Surrogate Adaptation	98	24%	
Sender accepts primary responsibility for adaptation	28		29%
Sender is patient/persistent	14		14%
Depends on receiver's mood/patience/well-being	12		12%
Sender observes receiver's nonverbals	11		11%
Sender uses shorter, more simple statements	10		10%
Sender probes for clarity	8		8%
Depends on sender's mood/patience/well-being	5		5%
Sender rephrases/reframes	3		3%
Sender uses concrete (versus abstract) statements	3		3%
Sender has an "aptitude" for this sort of communication	3		3%
Depends on sender's comfort level	1		1%
Sender Education and Acceptance	95	23%	
Sender educates self re person/disease	32		34%
Sender accepts person/disease	21		22%
Sender uses props/reminders	14		15%
Sender modifies environment	13		14%
Receiver is familiar w/environment	8		8%
Sender models appropriate communication	3		3%
Sender uses redirection	2		2%
Sender reinforces receiver behavior	2		2%
Validation	42	10%	
Sender demonstrates respect for receiver	16		38%
Sender does not attempt to "bring receiver into present reality"	8		19%
Receiver "understands"	5		12%
Sender talks more of distant past	5		12%
Receiver acknowledges sender	4		10%
Sender demonstrates empathy toward receiver	4		10%
Not Categorized	3	<1%	
Sender tries to "bring receiver into present reality"	1		33%
No change from one time to the next	1		33%
Receiver "perks up"	1		33%

- Sender uses direct eye contact (30);
- Sender accepts primary responsibility for adaptation (28);
- Sender uses appropriate touch (22); and
- Sender accepts person/disease (21).

Other responses, along with the total number of instances of occurrence of each response across all categories are as follows:

- Sender demonstrates respect for receiver (16);
- Sender uses receiver's name; sender and receiver are one-on-one; sender "slows down" demeanor (15);
- Sender is patient/persistent; sender uses props/reminders (14);
- Sender modifies environment; sender sits/stands close to receiver (13);
- Sender uses appropriate humor; depends on receiver's mood/patience/well-being (12);
- Sender observes receiver's nonverbals; receiver is comfortable with sender (11);
- Sender uses shorter, more simple statements; sender is "present"/focused (10);
- Receiver is familiar with environment; Sender probes for clarity; Sender does not attempt to

"bring receiver into present reality"; sender is intuitive or feels connection/intensity/emotion (8);

- Sender uses calm/low/soft voice; sender "cares more" (7);
- Receiver "understands"; depends on sender's mood/patience/well-being; sender talks more of distant past; sender sits/stands directly in front of receiver (5);
- Receiver acknowledges sender; sender and receiver are on same eye-level; sender demonstrates empathy toward receiver (4);
- Sender models appropriate communication; sender rephrases/reframes; sender uses concrete (versus abstract) statements; sender has an "aptitude" for this sort of communication (3);
- Sender smiles; receiver smiles; sender uses redirection; sender reinforces receiver behavior; sender expresses own vulnerability (2);
- Sender tries to "bring receiver into the present reality"; no change from one time to the next; receiver "perks up"; depends on sender's comfort level (1).

These common themes further arranged themselves into four general categories, as follows:

- Immediacy
- Surrogate Adaptation
- Sender Education and Acceptance
- Validation

Additionally, there were three "outliers," listed as "Not Categorized." Within the four larger, primary categories, the greatest number of responses (167, or 41% of total responses) fell into the category that indicates immediacy behaviors on the part of the sender facilitate effective communication. A large number of responses (98, or 24% of total responses) also support Haden's (1997) theory about "surrogate adaptation," and nearly as many responses (95, or 23% of total responses) stress the importance to effective communication of the sender educating her- or himself about, and accepting, both the person and the disease. A smaller, though still significant number of responses (42, or 10% of total responses) supports the importance of validation techniques to effective communication.

CHAPTER FOUR: Discussion

Four primary parallels can be drawn from this study to techniques and strategies advocated in the literature. The first has to do with the importance to effective communication of immediacy behaviors. Those sender behaviors that indicate warmth, openness, and responsiveness on the part of the sender toward the receiver were mentioned by respondents almost twice as many times as any others, as being those behaviors that facilitate effective communication. Simply stated, it appears that respondents' demonstration of "liking" for the receiver may have resulted in the receivers' demonstration of "liking" for the sender; the result of their positive interaction was apparently a climate that fostered open and successful communication.

A second parallel is that of the concept of "surrogate adaptation" (Americo, 1998; Haden, 1997). For purposes of the current study, the concept of surrogate adaptation means this: in dyadic communication, there exists an ebb and flow that allows either participant to "fill in the gaps" by adapting in some respect, when the other one is unable or unwilling to do so. When dyadic communication involves one participant whose abilities for receptive and expressive communication are severely compromised, the

other party must develop an acute awareness of her or his *increased requirement* to adapt in order for continued communication to be effective. Thus, the sender in the communication dyad under discussion adapts more often and to a greater degree than does the receiver. Respondents in the current study stressed the imperative nature of such awareness of the requirement to adapt in order for successful communication to occur.

The third parallel has to do with the importance of the sender's knowledge, understanding, and acceptance of AD and of the receiver as an individual. It is notable that education and acceptance ranked first and fifth, respectively, in the number of times each was directly mentioned by respondents. The reasoning here appeared to be, "If I know what to expect, then I will also know what I need to learn in order to be an effective communicator. Having that knowledge allows me to let go of fear, to accept what is happening, and to move forward."

Communication breakdown ranks among the top four stressors in measures of caregiver burden. Therefore, it is important to understand that care providers who are successful communicators are also those care providers who recognize the need for education and acceptance. It appears that the care provider who knows more about AD and the care

receiver is also more able to understand both the disease and the care receiver who has the disease. This knowledge and understanding allows the sender to modify her or his communication strategies and techniques in order to facilitate effective communication. These two factors may open the pathway to decreased stress and increased well-being for both the care provider and the care receiver.

The fourth parallel is that of validation. Techniques used by the validating care provider (Touzinsky, 1998) facilitate effective communication because they provide an environment of unconditional acceptance and respect. Validation tells the care receiver, "What you experience right now, at this very moment, is reality." Within such an environment, the receiver is able to let go of the fear of not being heard and comes to realize she or he is understood. This information is also in line with Beach & Kramer's finding that care providers feel validation strategies are useful for "developing trust and conveying a sense of empathy" (1999, p. 20). A climate of trust and empathy lay the important groundwork for effective communication to occur.

4.1 Study Limitations

Prior to further discussion of findings, it is important to note that the small sample size of this study does limit its generalizability. However, the results of this study, in combination with the similar results of Beach & Kramer's (1999) study, lend support for the assertion that future long term field study is appropriate, and that such study would "yield a more complete understanding of communication efforts" (Beach & Kramer, 1999, p. 19) than presently exists.

4.2 Alignment with Current Knowledge

Most of the communication strategies cited by respondents in this study are similar to those reported in available literature. Data gathered for the current study supports results of earlier studies and appears to validate communication techniques and strategies put forth as a result of those studies (*CHAPTER ONE*, this document).

Extant literature recommends a multitude of techniques to facilitate effective communication between a care provider and a care receiver who has AD. Even so, there is a dearth of literature that speaks to care providers' perceptions about the efficacy of those techniques. Review of the literature reveals that one other study was

undertaken recently in an attempt "to begin to understand the 'insider's perspective' regarding communication experiences between formal care providers and residents with dementia" (Beach & Kramer, 1999, p. 19).

The current study is similar in intent to the one conducted by Beach and Kramer, and findings in the current study both support and enlarge upon results of Beach & Kramer's exploration. It is important to note, however, that the two studies differ in several respects:

- Sample size and demographics: Beach & Kramer's (B&K) sample consisted of eight professional care providers, all of whom were employed in the same agency. B&K respondents were geographically homogeneous. The sample for the current study consisted of 17 care providers, seven of whom were professionals employed by different agencies, and 10 of whom were lay care providers. Respondents represented different geographical areas and were from varied cultural milieus.
- Data collection: B&K gathered data via face-to-face interviews. The current study utilized 13 face-to-face interviews, three on-line interviews, and one telephone interview.

- Data interpretation: In the B&K study, "follow-up efforts were not undertaken and therefore, confirmability checks of the data via respondent clarification were not possible" (Beach & Kramer, 1999, p. 19). In the current study, the researcher engaged in a follow-up meeting or contact with each respondent to confirm and clarify data; and
- Study limitations: B&K study reports, "while gaining the caregiver's perspective is useful, the communication strategies described were not validated or tested for efficacy or effectiveness" (p. 19). The current study holds that the caregiver's perspective *is* the validation of efficacy or effectiveness. In other words, for purposes of the current study, if caregivers use the strategy, *and* if they perceive that strategy to result in effective communication when they use it, *and* if they also perceive it to be effective when they observe others using it, then the claim of that strategy to effectiveness is valid.

Differences between the two studies having been noted, it remains that there are significant similarities within

the findings of the two studies. Contained in the results of the current study are five response categories that are analogous to six response categories in the B&K study (TABLE 3.6). These five categories are as follows:

- Sender educates self re person/disease (B&K "Connection to Resident's History," p. 12);
- Sender does not attempt to "bring receiver into present reality" (B&K "Confirming the Resident's Reality," p. 13);
- Sender observes receiver's nonverbals (B&K "Nonverbal Communication Sensitivity," p. 16 and "Understanding Nonsensical Language," p. 18);
- Sender uses appropriate touch (B&K "Professional Use of Touch," p. 17); and
- Sender has an "aptitude" for this sort of communication (B&K "Personal Instinct vs. Professional Training," p. 17).

4.3 Conclusion

Disorders of language (including AD) adversely affect the communication abilities of both the person with AD and the care provider. Those adverse effects diminish the quality of life for both parties. As Sabat states, "It is clear care should be taken not to characterize [persons

with AD] as being unable to communicate. The challenges associated with caring for [persons with AD] could be partly addressed through helping caregivers to communicate more effectively" (1997, p. 344, 352).

If care providers for persons with AD are to communicate effectively with the care receivers, it is vital that we attend to the learning of all available techniques and strategies that have been demonstrated to result in effective communication. It is critical that we become proficient in the use of those strategies through education and practice. We must reach an acceptance of both the disease and the individuals who suffer from it in order to validate their realities. It is imperative for us to acknowledge the requirement that we perform the greater degree of adaptation in our communication with a person who has AD.

There were no "new" strategies, no previously unmentioned communication techniques, uncovered by the current study. Responses offered by participants in this investigation clarify that we truly do have access to the basic tools necessary for effective communication. However, what *was* uncovered is vitally important: there is truly "something" that goes beyond the acquisition and use

of communication strategies and techniques, and that results in effective communication between a care provider and a care receiver with AD.

A few respondents alluded to the essence of that "something" when they mentioned intuition and empathy, and when they said that "some people just seem to have an aptitude for this sort of communication." Beach and Kramer also address the "something" when they note, "one must possess the instinct rather than be trained to be successful at learning the language" (1999, p. 22).

What is that "something?" It is embodied in the concepts of acceptance and understanding, of validation, of knowledge of the requirement to adapt during communication; it is comprised of empathy and openness and vulnerability and unconditional positive regard. It cannot be taught, at least not in the sense that one teaches specific techniques and strategies, yet it must be learned and practiced in order for effective communication to occur. The current study validates the effectiveness of techniques and strategies put forth to date. Further, responses offered by study participants prod us with the awareness that, in order to communicate effectively with a person who has AD,

we must fully and completely integrate those existing tools with our own humanity.

Appendix One: Criteria for Selection of Respondents (Lay Care Providers)

1. Does this person currently provide, or has this person within the last year provided, care in a **non-professional** capacity for at least one person with Alzheimer's disease? Yes _____ No _____

2. Does this person identify himself or herself as the primary care provider?

   Yes _____ No _____

3. Is this person willing to talk about her or his experience re communicating with the person(s) who has/have Alzheimer's disease? Yes _____ No _____

4. Is this person able clearly to verbalize her or his experience re communicating with the person(s) who has/have Alzheimer's disease? Yes _____ No _____

5. Have I explained to this person the purpose for this study? Yes _____ No _____

6. Does this person understand my explanation? Yes _____ No _____

If the response to **every** one of the above questions is "Yes," request an interview date and time. If the response to **any** one of the above questions is "No," do one of the following: (1) If the response to the question(s) **can** be changed to "Yes" by some **interviewer** action (e.g., re-explanation), attempt to do so. (2) If the response to the question(s) **cannot** be changed to "Yes" by some **interviewer** action, thank the person for her or his time and advise the person of the reason for discontinuing the process.

Appendix Two: Criteria for Selection of Respondents (Professional Care Providers)

1. Does this person provide care in a **professional** capacity for at least one person with Alzheimer's disease? Yes _____ No _____

2. Does this person provide such care at least one day per week?

   Yes _____ No _____

7. Is this person willing to talk about her or his experience re communicating with the person(s) who has/have Alzheimer's disease? Yes _____ No _____

8. Is this person able clearly to verbalize her or his experience re communicating with the person(s) who has/have Alzheimer's disease? Yes _____ No _____

9. Have I explained to this person the purpose for this study? Yes _____ No _____

10. Does this person understand my explanation? Yes _____ No _____

If the response to **every** one of the above questions is "Yes," request an interview date and time. If the response to **any** one of the above questions is "No," do one of the following: (1) If the response to the question(s) **can** be changed to "Yes" by some **interviewer** action (e.g., re-explanation), attempt to do so. (2) If the response to the question(s) **cannot** be changed to "Yes" by some **interviewer** action, thank the person for her or his time and advise the person of the reason for discontinuing the process.

Appendix Three: Consent to Interview

I agree to participate in an interview about my communication experiences with someone who has Alzheimer's disease. The interviewer has explained to me that, by interviewing individuals who provide care for a person who has Alzheimer's disease in either a lay (nonprofessional) or a professional capacity, she seeks to answer the question, *"How do individuals who communicate regularly, on either a professional or non-professional basis, with a person who has Alzheimer's disease adapt their messages in order to facilitate communication?"*. I have discussed the research question with the interviewer and I have had the opportunity to ask questions about anything I do not understand. I understand the interviewer is a graduate student in the Department of Communication Studies at The University of Montana, and information she obtains during this interview will become part of her Master's Thesis.

I understand that my responses will remain completely confidential, that the interview will take approximately one hour, and that this interview will be tape recorded. Neither my name nor any other identifying information will be included with my responses, and the interviewer will not attach my signed consent form to the typed transcript. I further understand the interviewer will contact me again after she has transcribed my interview, for the sole purpose of ensuring accuracy of the information contained in that transcription. When the interviewer has ensured accuracy of the information, she will erase the tapes. The tapes as well as the information contained in them will remain the property of the interviewer. The interviewer has offered to provide me with a copy of my interview transcript if I request that she do so.

During the interview I can decline to answer any question the interviewer asks. If I want to take a break or if I want to discontinue the interview at any time, I will inform the interviewer and we will stop. The interviewer has shown me how to turn off the tape recorder, and the tape recorder is placed where I can reach it. The interviewer has provided me with a copy of this consent form.

I agree to allow the interviewer to quote me directly in those instances where to do so will in some manner contribute to the quality and depth of this study. I understand my name will not be used and that I will have an opportunity to view quoted material prior to my approving or disapproving its use. *Yes* _____ *No* _____

The interviewer has explained to me that, although I may find some of the questions uncomfortable, there is no risk to me in responding to them. *Although no risks are foreseen as a result of your participation in this interview The University of Montana requires the following statement:* ****University of Montana Liability Statement:** In the event that you are injured as a result of this research you should individually seek appropriate medical treatment. If the injury is caused by the negligence of the University or any of its employees, you may be entitled to reimbursement of compensation pursuant to the Comprehensive State Insurance Plan established by the Department of Administration under the authority of M.C.A., Title 2, Chapter 9. In the event of a claim for such injury, further information may be obtained from the University's Claims Representative or University Legal Counsel.

_____ _____

Participant Today's Date

_____ _____

Interviewer Today's Date

Interview Code: _____

Appendix Four: Interview Guide

1.) **(Subjective--successful vs. non-successful communication).** Are you able sometimes to communicate more successfully with X_____ than you are at other times? If so, how is the successful communication different from the less successful communication?

2.) **(What makes it different?)** Do you know what circumstances occur or what you say or do that makes your communication more successful sometimes than it is other times?

3.) **(Specific episode between respondent and PWAD).** Can you describe a specific interaction between yourself and X_____ where your communication was successful? If so, why was it successful?

4.) **(Intra-respondent differences).** Are you aware of any ways in which your communication with X_____ became different after the onset of Alzheimer's disease from the way it was before? If so, can you describe those differences?

5.) **(Inter-communicator differences--observed communication).** Have you had the opportunity to observe other people when they communicate with a person who has Alzheimer's disease? Have you noticed some people who communicate more successfully than others? If so, can you describe the differences between the more successful communicators and the other communicators?

Appendix Five: Respondent Demographics

(Please note: Your response to the following questions is **not** required. However, your responses may help to inform future research on this topic.)

1). What is your age?

Under 25 _____
26 to 35 _____
36 to 45 _____
46 to 55 _____
56 to 70 _____
Over 70 _____

2). What is the approximate age of the person with Alzheimer's disease for whom you provide care?

Under 55 _____
56 to 65 _____
66 to 75 _____
Over 75 _____

3). What is your gender?

Male _____ Female _____

4). What is the gender of the person who has Alzheimer's disease and for whom you provide care?

Male _____ Female _____

5). What is your relationship to that person?

_____

_____

6). How many hours per week do you spend with this person? _____

Appendix Six: Online Interview Form

Date:
Interview Code:

Are you able sometimes to communicate more successfully with X_____ than you are at other times?

How is the successful communication different from the less successful communication?

Do you know what circumstances occur or what you say or do that makes your communication more successful sometimes than it is other times?

Can you describe a specific interaction between yourself and X_____ where your communication was successful?

If so, why was it successful?

Are you aware of any ways in which your communication with X_____ became different after the onset of Alzheimer's disease from the way it was before?

If so, can you describe those differences?

Have you had the opportunity to observe other people when they communicate with a person who has Alzheimer's disease?

Have you noticed some people who communicate more successfully than others?

If so, can you describe the differences between the more successful communicators and the other communicators?

Appendix Seven: Online Consent to Interview Form

I agree to participate in an interview about my communication experiences with someone who has Alzheimer's disease. The interviewer has explained to me that, by interviewing individuals who provide care for a person who has Alzheimer's disease in either a lay (nonprofessional) or a professional capacity, she seeks to answer the question, *"How do individuals who communicate regularly, on either a professional or non-professional basis, with a person who has Alzheimer's disease adapt their messages in order to facilitate communication?"*. I have discussed the research question with the interviewer and I have had the opportunity to ask questions about anything I do not understand. I understand the interviewer is a graduate student in the Department of Communication Studies at The University of Montana, and information she obtains during this interview will become part of her Master's Thesis.

I understand that my responses will remain completely confidential, that the interview will take approximately one hour, and that this interview will be tape recorded. Neither my name nor any other identifying information will be included with my responses, and the interviewer will not attach my signed consent form to the typed transcript. I further understand the interviewer will contact me again after she has transcribed my interview, for the sole purpose of ensuring accuracy of the information contained in that transcription. When the interviewer has ensured accuracy of the information, she will erase the tapes. The tapes as well as the information contained in them will remain the property of the interviewer. The interviewer has offered to provide me with a copy of my interview transcript if I request that she do so.

During the interview I can decline to answer any question the interviewer asks. If I want to take a break or if I want to discontinue the interview at any time, I will inform the interviewer and we will stop. The interviewer has shown me how to turn off the tape recorder, and the tape recorder is placed where I can reach it. The interviewer has provided me with a copy of this consent form.

I agree to allow the interviewer to quote me directly in those instances where to do so will in some manner contribute to the quality and depth of this study. I understand my name will not be used and that I will have an opportunity to view quoted material prior to my approving or disapproving its use. ***Yes*** ***No***

The interviewer has explained to me that, although I may find some of the questions uncomfortable, there is no risk to me in responding to them. *Although no risks are foreseen as a result of your participation in this interview The University of Montana requires the following statement:* ****University of Montana Liability Statement:** In the event that you are injured as a result of this research you should individually seek appropriate medical treatment. If the injury is caused by the negligence of the University or any of its employees, you may be entitled to reimbursement of compensation pursuant to the Comprehensive State Insurance Plan established by the Department of Administration under the authority of M.C.A., Title 2, Chapter 9. In the event of a claim for such injury, further information may be obtained from the University's Claims Representative or University Legal Counsel.

Participant:
Today's Date:

Interviewer:
Today's Date:

Interview Code:

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